



Transforming Cancer Services Team

Report on the transforming primary care for people living with and beyond cancer events

October 2017

Supported by and delivering for London's NHS, Public Health England and the Mayor of London

Acknowledgements

The Transforming Cancer Services Team for London (TCST) and the Pan London Living with and Beyond Cancer Partnership Board are grateful to Macmillan Cancer Support for funding the events and for their continued support for the living with and beyond agenda. We would like to thank the speakers and facilitators who gave us their time, expertise, support and contributed to the effective running of the event.

A special note of thanks goes to David Jillings and Chris Arthur from Pelvic Radiation Disease Association for their thought-provoking testimonies that provided the backdrop to cancer patient experiences. We would also like to thank Charlene Onofiok who's organizational and hosting skills ensured the events ran smoothly.

Finally, huge thanks go to the patients and healthcare delegates who not only attended and actively participated in the discussions but provided valuable and honest input to the discussions.

1. Overview

Although more people are surviving cancer, London continues to have the poorest outcomes in the UK. The 2015 Cancer Patient Experience Survey showed some of the lowest scored questions in London were related to support from primary and community care for patients and their families living with the cancer *after* discharge or transfer from the hospital.

In 2015, the Transforming Cancer Services Team has developed a vision of cancer as a long term condition. The vision supports the Healthy London Partnership's primary care transformation commissioning framework and NHS England's Five Year Forward View to enhance quality of life for people with long term conditions. One of the outputs of the vision is a 4-point model for the holistic long-term management of cancer patients what is being adopted by STPs across the London region.

The TCST conducted a series of training needs assessments in 2016, to identify gaps across the living with and beyond cancer pathway. In the form of an online survey, 138 responses were received from London-based GPs and primary care nurses. The most notable finding was related to training needs around the consequences of cancer treatment, particularly cardiovascular and osteoporosis.

Fewer than 6% of GPs and 4% of nurses had received general education on the consequences of cancer treatment that patients may develop over time. 41% of GPs and 36% nurses stated that they received a small amount of training on the subject. When asked if they would like further training, the majority of respondents, both GPs and nurses, said they would welcome the opportunity. 90% of nurses and 94% of GPs wanted further training on the management of cardiovascular consequences of cancer treatment, 88% nurses and 93% GPs wanted management of bone consequences and 86% and 88% wanted management of side effects such as urinary and sexual problems and cancer related fatigue.

The content of the primary care education events was based on the findings of the training needs assessments. Three identical events, to allow attendance, were arranged on the 20th June, 11th July and 13th July 2017. In total 75 people attended the events.

2. Delegate recruitment and attendance

In order to have an open discussion regarding cancer as a long term condition and appropriately support patient in primary care, attendance was sought from the Sustainability and Transformation Partnerships (STPs) that fall with the geographical remit of the Transforming Cancer Services Team:

- North Central London STP
- North East London STP
- South East London STP
- South West London STP
- North West London STP
- West Essex CCG (part of Essex STP)
- Pan London (for delegates that were not assigned to any particular area of London or represented two or more geographical areas)

Invitations for the event were sent out to all known STP and CCG cancer managers, Macmillan GPs, Cancer Lead GPs, charity partners, mental health colleges, allied health professionals, primary care nurses and patient groups from across London.

A breakdown of the delegates is outlined in Chart 1 below and Chart 2 outlines attendance by job title and by STP.

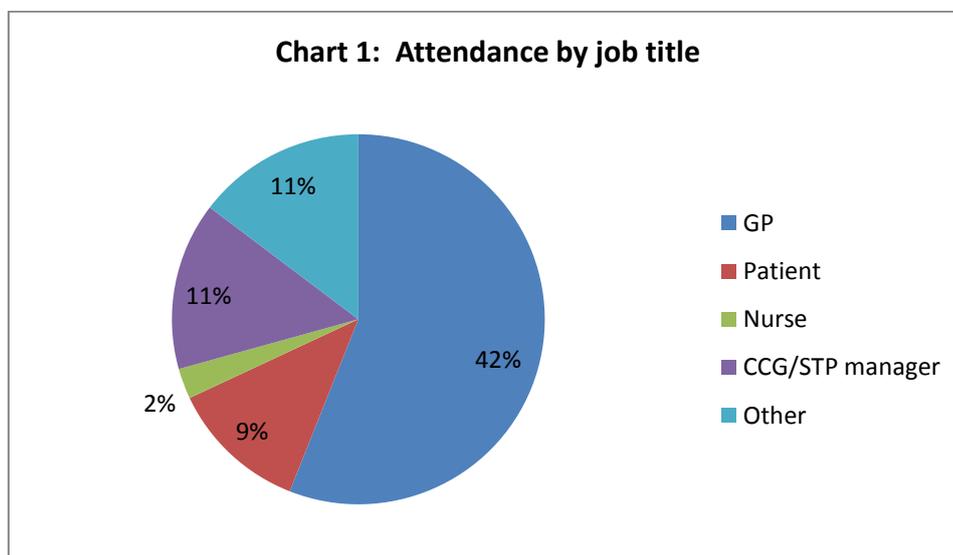
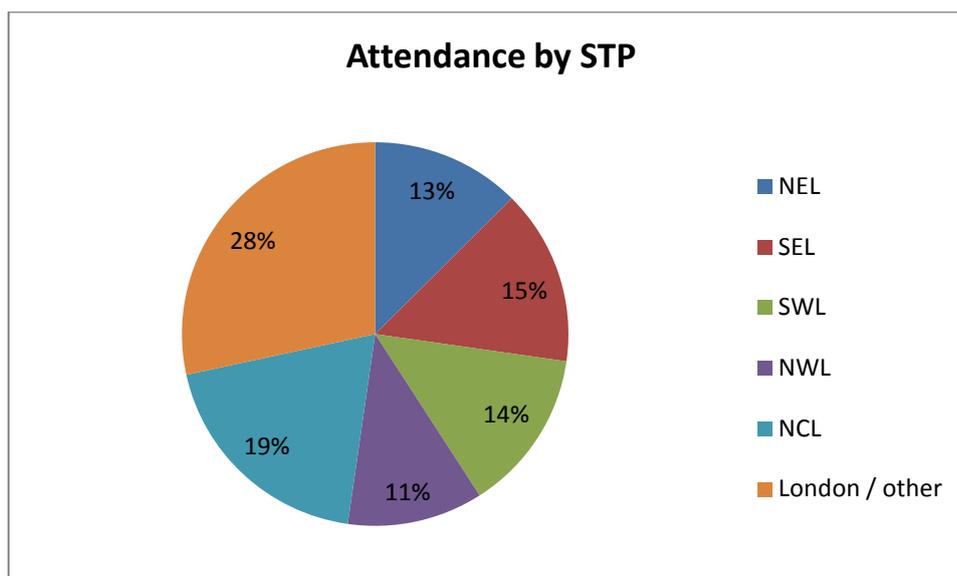


Chart 2 below outline the geographical areas represented at the event.



3. Event programme

The one day programme was repeated over three days. The agenda was split between a clinical education session for primary and community care health care professionals around the long term management of cancer patients and an afternoon strategic and commissioning session for cancer lead GPs, commissioners and STP leads.

The agenda (see Appendix 1) was split between scene setting to ensure the audience received an update on the direction of travel for the Living with and Beyond Cancer workstream and the position for London in terms of meeting the objectives set out by NHS England's Five Year Forward View. The event was supported by two patient guest speakers who outlined the psychological and physical consequences of cancer treatment and the support they needed from primary care after treatment.

Speakers

Dr Pawan Randev, GP Education Lead, Transforming Cancer Services Team for London (29th June)

Dr Afsana Safa, Cancer Lead GP NWL STP and GP Lead, Transforming Cancer Services Team for London (11th July)

Dr Anthony Cunliffe, Macmillan GP Adviser, London and South East Coast and GP Lead, Transforming Cancer Services Team for London (13th July)

Annie Reilly, Partnership Quality Lead, Macmillan (29th June)

Donal Gallagher, Partnership Manager, North East London (11th July)

Dan Callanan, Partnership Manager; Macmillan (13th July)

Chris Arthur (29th June) and **David Jillings** (11th and 13th July), Service Users, Pelvic Radiation Disease Association

Dr Karen Robb, Macmillan Rehabilitation Clinical Lead, Transforming Cancer Services Team for London

Dr Philippa Hyman, Macmillan Mental Health Clinical Lead and Clinical Psychologist, Transforming Cancer Services Team for London

Dr Tony Brzezicki, Chair of Croydon CCG, Co-Chair London Cancer Commissioning Board

Liz Price, Associate Director for Loving with and Beyond Cancer, Transforming Cancer Services Team for London

Sarita Yaganti, LWBC Strategy Implementation Lead, Transforming Cancer Services Team for London

The morning session ended with an interactive session where delegates were asked what messages and recommendations they want taken to the commissioners. In terms of the support they need to manage cancer patients as part of long term conditions, comments captured include.

- Treatment Summaries and holistic needs assessments are not being received by primary care clinicians. A recommendation is for a request to be sent to the hospital if the appropriate information around consequence of treatment is not received by the GP. This function could be set up via existing communications clinical systems such as Kinesis that is used across SWL.

- Contractual discussions with CCGs and Federations around implementation of the TCST's 4 Point CCR Model. This includes:

1. Improved coding for patients being added to the practice's cancer register (as per QOF CAN 001)
2. Appropriately timed appointments to support the holistic cancer care reviews (as part of QOF CAN003)
3. Holistic cancer care reviews at the end of a phase of treatment (where funding is available)
4. Include cancer patients as part of long term conditions management service specifications (as per NICE Guidance 56 on multi-morbidity management and care planning).

- There is a variation on the availability of protected learning times for GPs and primary care nurses. Some CCGs offer a more robust education and training programme than others and there is a general gap for training and educational session on the long term clinical effects on cancer patients and carers. The Macmillan primary care community and Cancer Research UK Facilitators are an available resource across London and West Essex. Working with Community Education Provider Networks (CEPNs), CCGs and federations are asked to mandate where possible educational sessions that cover elements the living with and beyond cancer modules.

- In particular, CCGs and CEPNs are asked to proactively support the Macmillan Primary Care Nurse Development course provided by the Royal Marsden School. Macmillan also covers the costs of backfill for practices.

- Access to local service directories should be made available on clinical systems for easy referral and signposting during appointment times to patients.

- Standardisation of clinical templates for holistic cancer care reviews and patient information letters, for example using Macmillan EMIS template for holistic CCRs or referring to the clinical content developed by the TCST.

- Work with patient groups and forums to drive delivery and quality of the Recovery Package. Empowering patients to request elements of the Recovery Package at the most appropriate time and to ensure carers needs are identified and met.

- As more and more people are living with and beyond cancer, a systematic and collaborative approach is needed to ensure that primary and community care services are sustainable.

4. Case studies

The case studies were based on the TCST's TNA survey findings related to questions around structuring holistic cancer care review at the end of active treatment and managing consequences of treatment. Examples of Treatment summaries and holistic needs assessments, which should be sent to the GP by the hospital as part of the Recovery package, were provided as reference.

Please see Appendix 2 for case studies. The case studies were split into two 20 minute round table discussions. The consequences of treatment session, led by Drs. Robb and Hyman and the service user story took place in between the two Part 1 and Part 2 of the case studies. The purpose of this was to provide a greater depth to reflection on current practice.

In Part 1 using the resources provided, delegates were asked to reflect on:

- What further info do they want from the patient?
- How would go about finding out they find more info?
- What would they do next?

For Part 2, delegates were asked to reflect on the talk by the service users and the psychological and physical impact experienced. Both David Jillings and Chris Arthur outlined the role primary care had in their care and what steps that could have been done in order to improve their quality of life.

In the same round tables as for Part 1, the delegates were asked what they would do differently.

The consequences of treatment session for all three events generated the most interaction between the speakers and the audience. The session overran leaving inadequate time for formal feedback however comments were scribed and collected in the feedback forms.

5. Headline summary of delegate feedback

64% of attendees (n=48) completed evaluation forms and these were collated after the events. Questions were focused particularly around the speakers, the content, the subject matter and behavior change. A summary of the findings are below:

- 98% of delegates thought the content of the event was either "excellent" or "good"
- 94% thought the quality of the speakers was either "excellent" or "good"

100% reported that the event was relevant to them with 85% of them outlining the presentations and the consequences of treatment section were the most useful. The remaining 15 % said that the whole event was useful.

The following charts outline the free text feedback from delegates around the content of the event and impact on behaviours going forward.

- Chart 1 outlined responses regarding the elements of the event that delegates found most useful
- Chart 2 outlines the free text elements of the event that delegates found least useful. The “other” comments (n=8) include, the agenda not including elements of palliative care, slides contain too much information, training needs assessment findings could have been summarized.
- Chart 3 outlines the responses from health care professionals who were asked what they would change when managing cancer patients.
- Seven patients attended the events, six of whom completed the feedback form. Chart 4 (n=6) outlines the question to patients on what they would need from their primary care practice. Responses include more proactive support from GP or practice nurse, better access to the GP, having a designated healthcare professional to co-ordinate care and to have the knowledge that the practice is there to support them during and after cancer diagnosis and treatment.

Chart 1

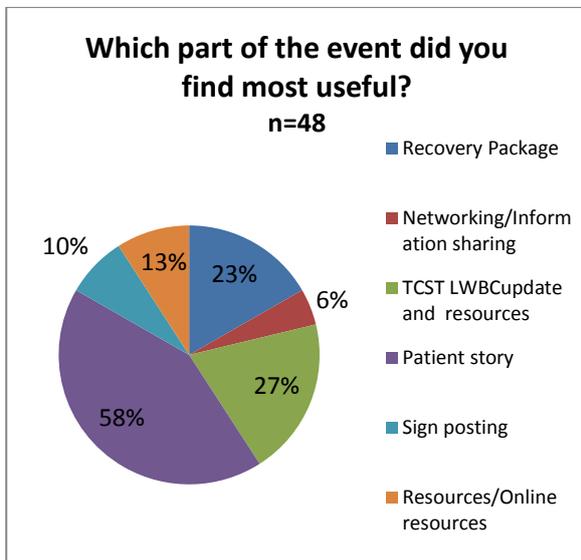


Chart 2

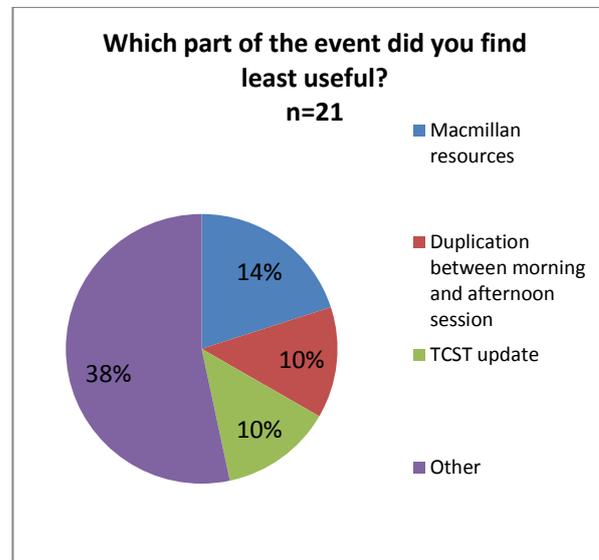


Chart 3

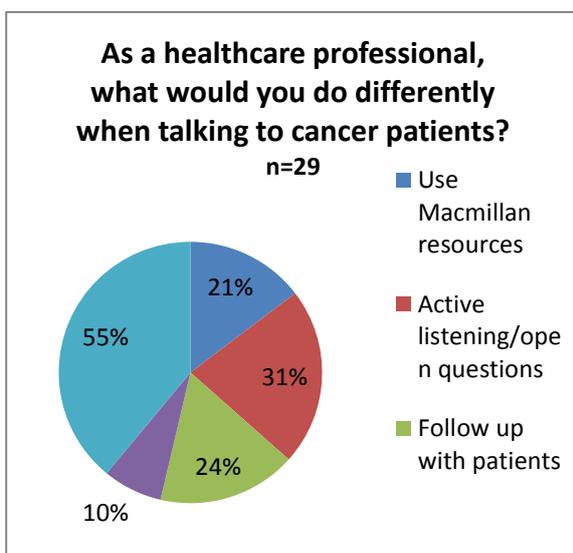
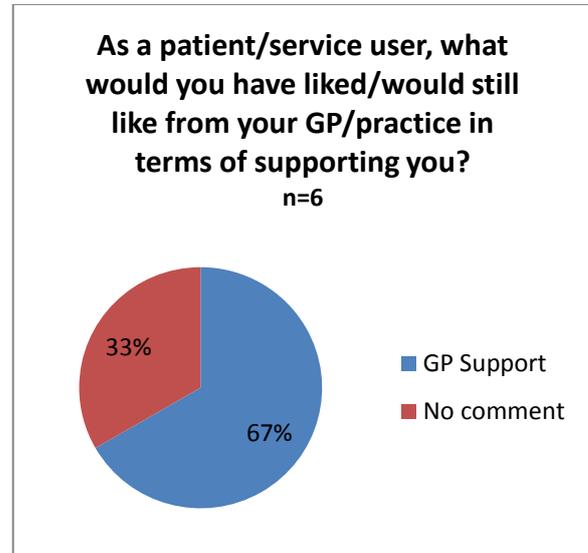


Chart 4



TCST continues to have discussions with STPs on the approach to cancer as a long term conditions. This includes adopting at least 3 interventions of the 4 point model (those that do not require additional funding) and strengthening access to community mental health services.

Furthermore, the slide deck used at the events is available for Macmillan GPs and Cancer Lead GPs as part of TCST's 'train the trainer' toolkit.

Other comments received:

"Really useful event. Need to reach more GPs. Many thanks"

"TCST should come to Greenwich and share this"

"Printing out short leaflets with easy to follow flyers for patients"

"Disseminate training at CCG / PTL when discussing rehab - how to access any specific referral pathways"

"Very powerful training event should be mandatory for all"

"Well done all. Please think about some enhanced service / incentive programme that brings primary and secondary care closer together for shared learning"

"Lots of info in a short timeframe but held my interest Useful actions for me to pick up with CCG colleagues"

6. Next Steps

A key aim of the event was to highlight the findings of the training needs assessment across primary and community care and to advise commissioners on the learning gaps identified.

The TCST will continue to support STPs and primary care professionals to deliver a sustainable holistic service to our patients. Much of this support will be in the form of working with STPs and CEPNs to strengthen the educational offer to those on the frontline. Both the TNA surveys and feedback from the primary care events have demonstrated training gaps and, with the right support and commitment, there is an opportunity to standardise good practice and reduce the variation in care for people affected by cancer.

Lessons learnt from the event include:

- For future events, the TCST will host the commissioning and clinical sessions on separate dates as the majority of the morning delegated stayed for the afternoon session and experienced duplication of some of the agenda items. Need a greater understanding on what commissioners need in order to improve attendance at future events.

- Produce bite-sized webinars focusing on the various elements of the LWBC pathway to allow greater access to resources, for example, developing a way of 'walking through' the recovery package using a patient story.
- Work with STPs/CCGs and Federations to empower practices to access specialist advice at tumour level, and to request treatment summaries and review of patients' holistic needs.
- Invite specialist clinicians or allied health professionals to talk about some of the consequences that can be managed in primary care and access to advice.

Transforming Cancer Services Team for London

Skipton House
1st Floor
80 London Road
SE1 6LH

Team email: England.TCSTLondon@nhs.net

TCST is part of the Healthy London Partnership, a collaboration between all London CCGs and NHS England London region to support the delivery of better health in London

 [@TCST_London](https://twitter.com/TCST_London)

APPENDIX 1: Agenda

Agenda: morning clinical session	
09:00	Registration
09:30	Welcome, Introductions and ice breaker <i>TCST GP leads; Transforming Cancer Services Team for London</i>
09:55	Living with and beyond cancer and the Recovery Package <i>Dr Pawan Randev, GP Education Lead, Transforming Cancer Services Team for London (29th June)</i> <i>Dr Afsana Safa, Cancer Lead GP NWL STP and GP Lead, Transforming Cancer Services Team for London (11th July)</i> <i>Dr Anthony Cunliffe, Macmillan GP Adviser, London and South East Coast and GP Lead, Transforming Cancer Services Team for London (13th July)</i>
10:25	Overview of online resources available for primary care professionals <i>Dr Pawan Randev, GP Education Lead, Transforming Cancer Services Team for London (29th June)</i> <i>Dr Afsana Safa, Cancer Lead GP NWL STP and GP Lead, Transforming Cancer Services Team for London (11th July)</i> <i>Dr Anthony Cunliffe, Macmillan GP Adviser, London and South East Coast and GP Lead, Transforming Cancer Services Team for London (13th July)</i>
10:35	Macmillan resources <i>Annie Reilly, Partnership Quality Lead, Macmillan (29th June)</i> <i>Donal Gallagher, Partnership Manager, North East London (11th July)</i> <i>Dan Callanan, Partnership Manager; Macmillan (13th July)</i>
10:50	Q&A
11:05	Refreshments break
11:20	Case Study
11:40	Consequences of cancer treatment <i>Chris Arthur (29th June) David Jillings (11th and 13th July), Service Users Pelvic Radiation Disease Association</i> <i>Dr Karen Robb, Macmillan Rehabilitation Clinical Lead, Transforming Cancer Services Team for London</i> <i>Dr Philippa Hyman, Macmillan Mental Health Clinical Lead and Clinical Psychologist, Transforming Cancer Services Team for London</i>
12:10	Case Study

12:30 -12:45	Reflections and close <i>What would you like us to take us to take to the commissioners?</i>
-----------------	--

Agenda: afternoon strategy and commissioning session	
14:00	Welcome, Introductions and ice breaker <i>Dr Tony Brzezicki, co-Chair of London Cancer Commissioning Board</i>
14:30	Cancer Commissioning for London <i>Dr Tony Brzezicki, co-Chair of London Cancer Commissioning Board</i>
14:50	Model of Care for LWBC and variation in provision and outcomes <i>Liz Price, Senior Strategy Lead, Transforming Cancer Services Team for London</i>
15:20	Refreshments break
15:35	Consequences of cancer treatment <i>Chris Arthur (29th June) David Jillings (11th and 13th July), Pelvic Radiation Disease Association</i> <i>Dr Karen Robb, Macmillan Rehabilitation Clinical Lead, Transforming Cancer Services Team for London</i> <i>Dr Philippa Hyman, Macmillan Mental Health Clinical Lead and Clinical Psychologist, Transforming Cancer Services Team for London</i>
16:05	Primary Care Development <i>Sarita Yaganti, Implementation Lead; Transforming Cancer Services Team for London</i>
16:25	Offer from TCST: how can we help? Interactive session looking at CCG and STP plans for LWBC
16:45- 17:00	Reflections and close

Appendix 2: Case study scenarios

Case study 1

Stan is a married 59 year old who is being treated for a recurrence of nasal melanoma. He retired from his job as a senior policeman 2 years ago in order to have time with his family. His daughters live nearby and his son is starting university in Scotland. During the surgery and radiotherapy he remained optimistic but has now lost weight and has regrets about having the additional treatment. He attended with his wife who is concerned about him

Case study 2

Sam is a previously fit 68 year old who was been treated for aggressive prostate cancer last year. The radiotherapy and surgery have worked and he is in remission. Since treatment Sam has noticed that he gets occasional rectal bleeding and diarrhoea. He was a keen bowls player but has let his club membership lapse. His second wife is supportive but Sam feels he is letting her down by not being more positive.

Case study 3

Sue is a 64 year old with treated breast cancer. Her reconstruction went well but she has found it hard to control her diabetes following previous chemotherapy. She is conscious of putting on weight. She is married to Joe, her second husband, who is well and is looking forward to his retirement at 60.

Having been an active lady, Sue is now aware she is more short of breath on walking up hills but knows it must be expected as she gets older.

She had looked after her own parents and has supported Joe's mother who has dementia.

Case study 4

Brenda is a 58 year old female who has undergone (L) mastectomy with axillary clearance and radiotherapy for breast cancer. She is now having chemotherapy.

Brenda is overweight and has a long history of pain secondary to osteoarthritis. She is recently widowed, lives alone and works full time as an administrator.

Case study 5

George is a 65 year old lawyer who is undergoing treatment for colorectal cancer. He underwent a left hemi colectomy and now has a colostomy in situ. He is nearing the end of his chemotherapy.

George is married, has several grandchildren and is a keen golfer. He is working reduced hours until his chemotherapy ends. Has a past medical history that includes asthma and a total hip replacement.

Case study 6

Fatima is 55 years old, she is married but her husband is currently abroad. She is in remission from thyroid cancer 8 years ago. She has type 2 diabetes and had a heart attack two years ago. She has an elderly mother to look after. She is extremely anxious when she has to attend any hospital consultations. Additionally she has lost weight and her husband is concerned that she does not interact with others.